

104TH CONGRESS
1ST SESSION

S. 459

To provide surveillance, research, and services aimed at prevention of birth defects, and for other purposes.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 22, 1995

Mr. BOND introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

A BILL

To provide surveillance, research, and services aimed at prevention of birth defects, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; FINDINGS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Birth Defects Prevention Act of 1995”.

6 (b) FINDINGS.—The Congress makes the following
7 findings:

8 (1) Birth defects are the leading cause of infant
9 mortality, directly responsible for one out of every
10 five infant deaths.

1 (2) Thousands of the 250,000 infants born with
2 a birth defect annually face a lifetime of chronic dis-
3 ability and illness.

4 (3) Birth defects threaten the lives of infants of
5 all racial and ethnic backgrounds. However, some
6 conditions pose excess risks for certain populations.
7 For example, compared to all infants born in the
8 United States, Hispanic-American infants are more
9 likely to be born with anencephaly spina bifida and
10 other neural tube defects and African-American in-
11 fants are more likely to be born with sickle-cell ane-
12 mia.

13 (4) Birth defects can be caused by exposure to
14 environmental hazards, adverse health conditions
15 during pregnancy, or genetic mutations. Prevention
16 efforts are slowed by lack of information about the
17 number and causes of birth defects. Outbreaks of
18 birth defects may go undetected because surveillance
19 and research efforts are underdeveloped and poorly
20 coordinated.

21 **SEC. 2. BIRTH DEFECTS PREVENTION AND RESEARCH PRO-**
22 **GRAM.**

23 Part B of title III of the Public Health Service Act
24 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
25 tion 317D the following new section:

14 “(b) CENTERS FOR EXCELLENCE FOR BIRTH DE-
15 FECTS PREVENTION RESEARCH.—

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1 “(2) AUTHORITY FOR AWARDS.—For purposes
2 of paragraph (1), the Secretary, acting through the
3 Director of the Centers for Disease Control, may
4 award grants or enter into cooperative agreements
5 with State departments of health, universities, or
6 other private, nonprofit entities engaged in research
7 to enable such entities to serve as Centers of Excel-
8 lence for Birth Defects Prevention Research.

9 “(3) APPLICATION.—To be eligible for grants
10 or cooperative agreements under paragraph (2), the
11 entity shall prepare and submit to the Secretary an
12 application at such time, in such manner and con-
13 taining such information as the Secretary may pre-
14 scribe, including assurances that—

15 “(A) the program will collect, analyze, and
16 report birth defects data according to guidelines
17 prescribed by the Director of the Centers for
18 Disease Control;

19 “(B) the program will coordinate States
20 birth defects surveillance and prevention efforts
21 within a region;

22 “(C) education, training, and clinical skills
23 improvement for health professionals aimed at
24 the prevention and control of birth defects will
25 be included in the program activities;

1 “(D) development and evaluation of birth
2 defects prevention strategies will be included in
3 the program activities, as appropriate; and

4 “(E) the program funds will not be used to
5 supplant or duplicate State efforts.

6 “(4) CENTERS TO FOCUS ON RACIAL AND ETH-
7 NIC DISPARITIES IN BIRTH DEFECTS.—One of the
8 Centers of Excellence shall focus on birth defects
9 among ethnic minorities, and shall be located in a
10 standard metropolitan statistical area that has over
11 a 60 percent ethnic minority population, is federally
12 designated as a health professional shortage area,
13 and has an incidence of one or more birth defects
14 more than four times the national average.

15 “(c) CLEARINGHOUSE.—The Centers for Disease
16 Control shall serve as the coordinating agency for birth
17 defects prevention activities through establishment of a
18 clearinghouse for the collection and storage of data and
19 generated from birth defects monitoring programs devel-
20 oped under subsections (a) and (b). Functions of such
21 clearinghouse shall include facilitating the coordination of
22 research and policy development to prevent birth defects.
23 The clearinghouse shall disaggregate data by gender and
24 by racial and ethnic groups, the major Hispanic

1 subgroups, non-Hispanic whites, African Americans, Na-
2 tive Americans, and Asian Americans.

3 “(d) PREVENTION STRATEGIES.—The Secretary, act-
4 ing through the Director of the Centers for Disease Con-
5 trol, shall award grants to or enter into cooperative agree-
6 ments with State departments of health, universities, or
7 other private, or nonprofit entities to enable such entities
8 to develop, evaluate and implement prevention strategies
9 designed to reduce the incidence and effects or birth de-
10 fects including—

11 “(1) demonstration projects for the prevention
12 of birth defects, including—

13 “(A) at least one project aimed at enhanc-
14 ing prevention services in a ‘high-risk area’ that
15 has a proportion of birth to minority women
16 above the national average, is federally des-
17 ignated as a health professional shortage area,
18 and has a high incidence of one or more birth
19 defects; and

20 “(B) at least one outcome research project
21 to study the effectiveness of infant interventions
22 aimed at amelioration of birth defects; and

23 “(2) public information and education programs
24 for the prevention of birth defects, including but not
25 limited to programs aimed at prevention of alcohol

1 and illicit drug use during pregnancy and promotion
2 of use of folic acid vitamin supplements for women
3 of childbearing age in a manner which is sensitive to
4 the cultural and linguistic context of a given commu-
5 nity.

6 “(e) ADVISORY COMMITTEE.—

7 “(1) ESTABLISHMENT OF COMMITTEE.—The
8 Secretary shall establish an Advisory Committee for
9 Birth Defects Prevention (in this subsection referred
10 to as the ‘Committee’). The Committee shall provide
11 advice and recommendations on prevention and ame-
12 lioration of birth defects to the Secretary and the
13 Director of the Centers for Disease Control.

14 “(2) FUNCTIONS.—With respect to birth de-
15 fects prevention, the Committee shall—

16 “(A) make recommendations regarding
17 prevention research and intervention priorities;

18 “(B) study and recommend ways to pre-
19 vent birth defects, with emphasis on emerging
20 technologies;

21 “(C) identify annually the important areas
22 of government and nongovernment cooperation
23 needed to implement prevention strategies;

24 “(D) identify research and prevention
25 strategies which would be successful in address-

1 ing birth defects disparities among the major
2 Hispanic subgroups, non-Hispanic whites, Afri-
3 can Americans, Native Americans, and Asian
4 Americans; and

5 “(E) review and recommend policies and
6 guidance related to birth defects research and
7 prevention.

8 “(3) COMPOSITION.—The Committee shall be
9 composed of 15 members appointed by the Sec-
10 retary, including—

11 “(A) four health professionals, who are not
12 employees of the United States, who have ex-
13 pertise in issues related to prevention of or care
14 for children with birth defects;

15 “(B) two representatives from health pro-
16 fessional associations;

17 “(C) four representatives from voluntary
18 health agencies concerned with conditions lead-
19 ing to birth defects or childhood disability;

20 “(D) five members of the general public, of
21 whom at least three shall be parents of children
22 with birth defects or persons having birth de-
23 fects; and

24 “(E) representatives of the Public Health
25 Service agencies involved in birth defects re-

1 search and prevention programs and represent-
2 atives of other appropriate Federal agencies, in-
3 cluding but not limited to the Department of
4 Education and the Environmental Protection
5 Agency, shall be appointed as ex officio, liaison
6 members for purposes of informing the Com-
7 mittee regarding Federal agency policies and
8 practices;

9 “(4) STRUCTURE.—

10 “(A) TERM OF OFFICE.—Appointed mem-
11 bers of the Committee shall be appointed for a
12 term of office of 3 years, except that of the
13 members first appointed, 5 shall be appointed
14 for a term of 1 year, 5 shall be appointed for
15 a term of 2 years, and 5 shall be appointed for
16 a term of 3 years, as determined by the Sec-
17 retary.

18 “(B) MEETINGS.—The Committee shall
19 meet not less than three times per year and at
20 the call of the Chair.

21 “(C) COMPENSATION.—Members of the
22 Committee who are employees of the Federal
23 Government shall serve without compensation.
24 Members of the Committee who are not employ-
25 ees of the Federal Government shall be com-

1 pensated at a rate not to exceed the daily equiv-
2 alent of the rate in effect for grade GS-18.

3 “(f) REPORT.—The Secretary shall prepare and sub-
4 mit to the Committee on Energy and Commerce of the
5 House of Representatives and the Committee on Labor
6 and Human Resources of the Senate a biennial report re-
7 garding the incidence of birth defects, the contribution of
8 birth defects to infant mortality, the outcome of implemen-
9 tation of prevention strategies, and identified needs for re-
10 search and policy development to include information re-
11 garding the various racial and ethnic groups, including
12 Hispanic, non-Hispanic whites, African Americans, Native
13 Americans, and Asian Americans.

14 “(g) APPLICABILITY OF PRIVACY LAWS.—The provi-
15 sions of this section shall be subject to the requirements
16 of section 552a of title 5, United States Code. All Federal
17 laws relating to the privacy of information shall apply to
18 the data and information that is collected under this sec-
19 tion.

20 “(h) AUTHORIZATION OF APPROPRIATIONS.—

21 “(1) For the purpose of carrying out sub-
22 sections (a), (b), and (c), there are authorized to be
23 appropriated \$15,000,000 for fiscal year 1996,
24 \$20,000,000 for fiscal year 1997, and such sums as

1 may be necessary for each of the fiscal years 1998
2 and 1999.

3 “(2) For the purpose of carrying out subsection
4 (d), there are authorized to be appropriated
5 \$15,000,000 for fiscal year 1996, \$20,000,000 for
6 fiscal year 1997, and such sums as may be nec-
7 essary for each of the fiscal years 1998 and 1999.

8 “(3) For the purpose of carrying out sub-
9 sections (e) and (f), there are authorized to be ap-
10 propriated \$2,000,000 for each of the fiscal years
11 1996 through 1999.”.

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